

ISSUE BRIEF

Outcome # 2: All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.

*Michigan Department
of Community Health*



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CHILDREN'S SPECIAL HEALTH CARE SERVICES STRATEGIC PLANNING 2008

This background brief presents an overview of the **medical home** status for children and youth with special health care needs in Michigan. It has been prepared as a step in assessing the readiness, capacity, and barriers to a fuller implementation of medical home for children and youth with special health care needs (CYSHCN) in Michigan. Members of the **Children's Special Health Services Advisory Committee (CAC) and other partners** have compiled this brief to document the current status of medical home in both the U.S. and Michigan. This brief was developed as background material in preparation for the April 16 and 17, 2008 Michigan CYSHCN Strategic Planning Meeting. The meeting will result in a five year strategic plan. The overarching goal is to address for Michigan the 10-year Action Plan to Achieve Community-based Service Systems for Children and Youth with Special Health Care Needs and Their Families (U.S. Department of Health and Human Services, 2001). The focus of the CSHCS Strategic Plan is on assessing Michigan's current status of reaching the 2010 outcomes for CYSHCN, exploring strategies with key stakeholders from across the state to achieve these outcomes and in developing a prioritized five year plan to get us there. This brief is specific to the federal Maternal and Child Health Bureau Outcome #2: **All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.**

Medical Home

Background

The 2010 Action Plan for Children with Special Health Care Needs (CSHCN) is a ten-year plan developed and promoted by the Maternal and Child Health Bureau (MCHB) in the Health Resources and Services Administration of the U.S. Department of Health and Human Services, and is endorsed by the American Academy of Pediatrics (AAP), Family Voices, the March of Dimes and over 50 other national organizations.

The Action Plan includes the specific outcome of coordinated, ongoing, comprehensive care within a medical home for all children with special health care needs by 2010. Work on this outcome is proceeding at both the state and national levels. At the present time, the definition for CYSHCN by MCHB and Michigan CSHCS do not fully coincide (see box). Michigan's CSCHS program provides medical and support services to eligible children. Due to budget constraints CSHCS cannot currently open up eligibility for medical care and treatment. The CSHCS program can, however, provide education and outreach to the broader CYSHCN population.

The document, *Healthy People 2010*, offers a set of health outcomes for the nation and reflects current health planning at the national level. The nation's health plan recognizes the key to improving care for CYSHCN lies in a systems approach to organizing and delivering services. Healthy People 2010 objective 16.23 is to "increase the proportion of states and territories that have service systems for children with special health care needs." Achieving this objective has been further defined by the federal MCHB as accomplishing six core outcomes (USDHHS, 2001):

1. Families of children with special health care needs will participate in decision making at all levels and will be satisfied with the services they receive.
2. **All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.**
3. All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
4. All children will be screened early and continuously for special health care needs.
5. Community-based service systems will be organized so families can use them easily.
6. All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.

Definition:

Children and Youth with Special Health Care Needs

National (MCHB)

Children and youth who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Michigan CSHCS

Michigan's CSHCS eligibility criteria for children and youth focuses almost exclusively on physical health conditions and services provided by pediatric sub-specialists.

This Issue Brief focuses specifically on Outcome #2.

The Michigan Story

Michigan has a long and proud history of making children with special needs a priority, dating back to the late 1800's when organized state-run services first were made available to "crippled children." In more recent history, the focus of the program has been medical care, treatment and support services for eligible children and some adults with one or more of approximately 2,500 physical-health-related diagnoses. The treatment and supports that the program provides must be specific to the qualifying condition(s). Except in unusual circumstances, CSHCS focuses on the services provided by pediatric or other sub-specialists and does NOT cover primary care services or providers unless they directly relate to the qualifying condition (e.g. pneumococcal vaccine covered for a child with Sickle Cell Disease, or a urinalysis ordered by the local pediatrician for a child with kidney disease whose specialist is 400 miles away).

A **medical home** is not a building, house or hospital, but rather an approach to providing health care services in a high-quality, cost-effective manner. Children and their families who have a medical home receive the care that they need from a pediatrician or other health care provider whom they trust. Pediatric health care professionals and parents act as partners in a medical home to identify and access all medical and non-medical services needed to help children achieve their maximum potential. Through this partnership, the pediatric clinician can help the family and patient access and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child/youth and family.

The American Academy of Pediatrics (AAP) believes that the medical care of infants, children and adolescents should be:

- accessible;
- continuous;
- comprehensive;
- family-centered;
- compassionate; and
- culturally effective

These characteristics define the medical home. (AAP, 2002)

"Medical Home" for CYSHCN is often a difficult concept to understand. It is important to realize that medical home is both a concept and a set of principles, and, as such, is difficult to define and measure. It is not as simple as having a "regular doctor," for example. The principles, while similar, must go further to appropriately address the needs of CYSHCN, such as the development of a comprehensive plan of care in conjunction with the family. There is growing endorsement of the medical home concept including statements by the AAP and the American Academy of Family Physicians (AAFP).

As part of the MCHB 2010 Action Plan, three specific action steps to achieving a medical home for all

CYSHCN are defined. The steps and some of the recommended strategies to achieving them are summarized below.

1. *Standardize the core elements of the medical home*

- Revise AAP definition of medical home.

- Establish outcome based rationale for the definitive elements of a medical home by developing consensus statements.
- Demonstrate the efficacy and feasibility of the medical home.
- Incorporate evidence-based definition of medical home in the training of health and health-related professionals.

2. *Promote the medical home approach*

- Provide analysis of medical home data.
- Incorporate medical home concepts into interdisciplinary training.
- Develop, describe and disseminate good models of coordination between primary and specialty care providers.
- Assist other professionals who work with children to assume their collaborative roles in assuring a medical home for all CSHCN.

3. *Achieve universal access to medical homes*

- Identify a statewide focal point to provide leadership in the development of medical homes.
- Convene a consortium of stakeholders.
- Expand efforts to link all children to medical homes.
- Review reimbursement for key elements of medical home.

Michigan and National Data

Family Data

The National Survey of CYSHCN (2005/2006) is a national telephone survey. Participants are those who report having a child with a special need. Persons beyond those with Michigan CSHCS coverage or eligibility for their children were interviewed. According to the survey:

- 45.9% of parents of CYSHCN in Michigan reported that their children have a medical home. This compares to 47.1% nationally.
- 48% indicated “Effective care coordination was received when needed.”

Generally families without a regular doctor or provider to help them will delay, forgo, or seek care from alternate providers such as emergency rooms.

Recent analysis of the 2003 National Survey of Children’s Health indicates parents of CYSHCN experience more stress. After adjustment for demographics, social support and type of insurance, parents of CYSHCN reported higher levels of stress with substantially higher levels in parents of children with behavioral health needs. Parents of children who meet all medical home dimensions (personal doctor or nurse, accessible, coordinated, comprehensive, family centered and culturally sensitive) reported less stress. Family-centered care and comprehensive care were medical home dimensions most associated with less stress for parents of CYSHCN.

Pediatrician Data

A national AAP survey was conducted in 2000 to determine the extent to which pediatricians were providing medical homes to CYSHCN. Pediatricians reported:

- 27% of children in their practices met the MCHB definition of CYSHCN;
- 94% reported providing 24-hour/7 days per week telephone access to their patients;
- 69% provided emergency care on evenings and weekends;
- 60% reported having Saturday appointments; and
- 43% reported weekday evening appointment times.

While a majority (71%) of pediatricians felt they always provided care coordination within the context of a medical home, only:

- 24% always contacted schools;
- 41% always discussed non-medical needs; and
- 19% always provided an appointment to discuss the results of sub-specialist consultations (AAP, 2000).

Michigan recently completed the 2006 Child with Chronic Care Condition Custom Survey, which included recently added questions related to medical home. Of The 852 respondents:

- 62.7% indicated that their child received care from more than one provider or health care service.
- 38.7% indicated that someone helped coordinate care amongst different providers or services.
 - When this same question was asked of clients receiving services through a Children's Multidisciplinary Specialty (CMS) Clinic, 69.6% indicated that someone from the CMS Clinic helped coordinate care.
 - Additionally 90.9% of the respondents, who were seen in a CMS Clinic, indicated that the CMS Clinic had developed a plan of care for their child.
- When rated by the child's health status (based on parent perception), the group receiving the **most assistance** with coordination of care was the group whose health status was rated as Fair/Poor (49.7%). The group receiving the **least amount of assistance** with coordination of care was the group whose health status was rated Excellent/Very Good (32.7%).
- The age group with the greatest amount of coordinated care was the 0-4 age group with 45.5% of respondents indicating that someone helped coordinate care amongst different providers or services.

Michigan 2006 Child with Chronic Care Condition Survey

- Surveyed 1,500 randomly selected CSHCS enrollees.
- Mixed mail and phone methodology.
- 852 valid responses; response rate of 58.5%.

Children Living in Rural Areas

One out of four (25%) of Michigan children live in rural geographic areas.

Because rural residents have a slightly higher risk for being medically underserved, Medical Home initiatives throughout the state may lead to increased access to coordinated care. Michigan is in the early stages of implementation of telemedicine. For much of rural Michigan, the addition of this benefit would significantly improve access to specialty services and would support primary care providers in their role as the medical home for CYSHCN. Michigan Medicaid is a leader in allowing for reimbursement of telemedicine services.

Personal Narrative

From the family point of view

My son is 6 months old. He has Down Syndrome. He was seen by a pediatric cardiologist soon after he was born and found to have a hole between the chambers of his heart, a VSD. He was given medicine for his heart for several months, but he no longer needs them.

Unfortunately, he has other problems unrelated to his heart. He has been hospitalized with pneumonia twice in the last two months and the doctors think it is from aspiration. We are still trying to figure out why. In the last three weeks, he has been in the hospital twice, to the emergency room for replacement of his nasogastric tube, to outpatient surgery to replace the tube another time, to the gastroenterologist's office once and to the pediatrician's office more often than I can count. We talked to the doctor on call at least 4 times last weekend. We are scheduled to see a pediatric surgeon next week. We have had conflicting recommendations regarding how much and when to feed him as well as conflicting recommendations about where the tube should be placed – stomach or small intestine.

My husband and I are exhausted. I am so tired I showed up at the pediatrician's office today to meet with a nutritionist only to learn that our appointment is next week! The doctor and the nutritionist saw us anyway. My son will probably need a gastrostomy tube. If he gets a feeding tube, we will work with the Early On for speech therapy, but he may need more therapy than Early On provides to maintain his oral skills. We will need to coordinate services from the educational world with his medical services.

I need someone to help me coordinate his care – someone who knows my son, knows our family, can keep up with his problems, and knows the specialists and the nutritionist and the therapists. I need someone to help us coordinate this team of professionals and someone to help us make the best decisions for our child – decisions that are good for his health and also fit into our family's life.

From the physician's point of view

DC is a 5 year old girl who had bacterial meningitis when she was two months old. Her brain was severely damaged and she now has profound cognitive impairment, cerebral palsy, and seizures. She has severe scoliosis but her bones are so brittle the surgeon recommends against placing rods along her spine. She cannot sit or even roll on her own. She lies still in whatever position she is placed. She is fed by gastrostomy tube and her airway has to be suctioned frequently because she cannot clear her secretions. She is given 8 different medications every day and uses pumps, suction machines, an oximeter, oxygen, wheel chair, tubing, formula, diapers and other goods that I monitor and prescribe.

DC's teacher contacted me last week because DC is having more frequent episodes of apnea and some of them are very long – she had one spell last week that lasted 4 minutes. Her teacher wants clear guidelines on what to do if DC stops breathing. DC's parents don't agree on DC's care, so the teacher is looking to me for the final word.

I know what to do medically for this child, but I need help coordinating her care. I need someone who can talk to the teacher and school nurse when they are available – they are no longer at school when I return my calls after 5 pm. I would like to sit down with her teacher, school nurse, and parents, but I don't have the time to organize a conference. We all need a clear care plan for DC – family, teachers, therapists, physicians, nurses and parents – a care plan that is complete and updated regularly.

Current Status in Michigan

Michigan was selected to be part of the National Center of Medical Home Initiatives for CYSHCN Medical Home Learning Collaborative (MHLC). The Learning Collaborative assembled a CSHCS interagency team to address issues associated with improving care for the growing population of CYSHCN. Michigan also attended the medical home website meeting supported by the Utah Department of Health. This meeting was important since supportive resources, such as websites, for primary care providers in their role as a medical home for CYSHCN have been determined to be a critical and an unmet need in Michigan.

CYSHCN Medical Home Learning Collaborative

Michigan Team included:

- Parent Participation Program (now known as the Family Center)
- AAP – Michigan Chapter
- Michigan State Medical Society
- Michigan Academy of Family Physicians
- University of Michigan
- Children’s Hospital of Michigan
- Spectrum Hospital
- Henry Ford Health System

Out of Michigan’s involvement in the 2003 Medical Home Learning Collaborative the following Vision was developed and agreed to by the participants:

Michigan Medical Home 2010 Vision

Every CYSHCN will have care coordinated through a medical home.

Medical Home Definition There will be a consensus definition of Michigan Medical Home agreed upon by stakeholders, including Parent Partners, physicians/providers, and payers used for policy, reimbursement and education.

Reimbursement

- The State will have established payment mechanisms for:
 - Care Coordination within the Medical Home; and
 - Physician activities that are necessary to carry it out.
- Medical practices will be required to qualify as a Medical Home for CSHCN in order to bill for providing these services.

Regionalized Support System There will be a regionalized system of Medical Home support to recruit, train and mentor new Medical Home practices.

Parent Partners There will be a regionalized system of Parent Partners to:

- Recruit, train, and mentor new Medical Home parent partners.
- Assess, connect to, and rejuvenate Parent Advisory structures in Regional Pediatric Centers.

- Spread the word and create demand for Medical Home for CYSHCN.
- Decision Support** (Resources for primary care providers serving CYSHCN): There will be a system of Decision Support led by Michigan Chapter, AAP (MCAAP) “Champions,” employing:
- Sub-specialty Advisory Panels;
 - Evidence-based guidelines;
 - “Just in time” mailed/faxed/e-mailed/web-based concise information; and
 - Readily available sub-specialists.

An outgrowth of the MHLC exercise is a cooperative project with the **Department of Pediatrics Henry Ford Health System (HFHS)**, with the following activities targeted specifically at assisting the State to increase physician capacity to provide medical homes for CYSHCN:

1. Determination of cost;
2. Trial of primary physician case manager reimbursement method;
3. Web-based care-coordination software;
4. Continuous Quality Improvement activities; and
5. Spread strategy.

HFHS has made a strong commitment to the concept of the medical home for CYSHCN. Dr. Tisa Johnson participated as a member of Michigan’s team in the Medical Home Learning Collaborative. She has implemented the model in her HFHS-based practice. HFHS now intends to replicate the model in many of the 18-24 HFHS pediatric practice sites. The project also includes an effort to determine the different costs involved in implementation and operation of the medical home for CYSHCN. The HFHS has long employed the **Continuous Quality Improvement (CQI)** activities emphasized in the MHLC. HFHS personnel will assist Dr. Johnson, as she employs CQI processes to integrate into her spread strategy, a well-defined strategy to incorporate CQI activities with primary care practices, Title V and families around medical home.

Another medical home project is directed toward **training medical residents** in the precepts of the medical home for children and youth with special health needs. The MCAAP Committee on Children with Special Health Care Needs has proposed a joint effort with the Residency Directors of the four Michigan State University (MSU) affiliated programs to create curriculum content that will assist the state in achieving two MCHB outcomes: 1) All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home; and 2) All children will be screened early and continuously for special health care needs.

A second project was started at MSU in the fall of 2006. This project involves two primary care pediatric practices – a faculty practice on the campus of MSU and a resident continuity clinic at the Ingham County Health Department. A nurse coordinator has been hired to provide **care coordination** for children and families and to manage the project. Children identified through the newborn screening program as well as others covered by CSHCS are the initial participants in the project. The Medical Home Index and Medical Home Family Index have

been administered to providers and parents to gather baseline data as well as to identify areas that need attention. Focus groups with parents of participating children are being held to gain more information from family members. To evaluate the effectiveness of the nurse coordinator intervention, participating children are randomly assigned to “intervention” and “control” groups. The nurse coordinator will work directly with families of children in the “intervention” group; children in the “control” group will continue to receive care coordination from their pediatrician and the office staff. Encounters and communications with family members, patients, primary care providers, specialists and clinic staff are logged to document the time and effort involved in care coordination.

Michigan has for many years contracted with local health departments to assist families in establishing **links to community services** and other related health services (e.g., specialty care, early intervention). Additionally, local CSHCS programs are funded to provide **care coordination and case management** including the development of plans of care. The role of local public health will be broadened to share their experience and knowledge of local resources by assisting with care coordination through the medical home.

The **Governor’s Great Start Initiative**, in seeking the result: “Infants and young children are physically healthy,” identifies as a primary indicator, the “number and percentage of children under age 6, with a regular medical home.” It is hoped that through this effort, additional emphasis and resources will also be directed toward the expansion of the medical home initiative.

Challenges/Barriers

1. Michigan continues to struggle to determine the cost of implementation of the medical home. Efforts are under way at both the HFHS pilot and the MSU/Ingham County project to better document the cost to help move more statewide implementation forward.
 - a. However, Michigan also continues to lag behind the rest of the country in regard to economic improvements. Michigan currently leads the nation in unemployment. Continued budget deficits have been a reality in Michigan for over four years with over \$3 billion cuts in the state general fund. There is no end in sight to the structural deficit that Michigan faces given its depressed economy that is over-reliant on the auto-industry. In fact, Michigan faced close to another \$1 billion deficit in FY 07. Additional funding to “jump-start” medical home is unlikely.
 - b. While there is little CSHCS can do to rectify this challenge, improved systems of care and coordination of systems and funding streams can help assure that fiscal soundness is maintained in the programs for CYSHCN.
 - c. It is essential that stakeholders work together to identify both costs and benefits of medical home to prove the firm assumption that medical home is, at a minimum, cost neutral and may produce health care savings.

2. Michigan is a very large state both in terms of square miles, population and numbers of pediatric and family medicine practices. Without a regionalized system of care, it will be very difficult for a state with lean resources to “spread” the medical home strategy statewide.
3. Without a reimbursement mechanism that recognizes the additional time and resources needed to support a medical home, it is unlikely that Michigan providers will be interested in participating.
4. Recent increased interest is resulting in multiple groups developing their own version of the medical home.
5. Electronic medical records are a key component and not yet available across the system. Without this, duplication, waste and confusion can occur.
6. The model needs to apply to the full spectrum of pediatric well and sick care and not just those who are eligible for CSHCS.
7. Financing, training, education, promotion and infrastructure are essential but currently missing.
8. Health care delivery continues to get more onerous (forms, prior authorizations etc.) as reimbursement declines.

Strengths/Opportunities for Improvement

1. There is momentum behind medical home and many willing partners. Michigan should seize the opportunity to use this momentum to build on and spread the concept.
2. Michigan already has many pieces in place to varying degrees such as the model used in the Children’s Multidisciplinary Specialty (CMS) clinics, telemedicine, strong residency training programs, local health departments who are experienced and able to support the effort.
3. NCQA standards are now available for certification of medical homes. This adds an important tool as well as credibility to the process, particularly for third party payers.
4. Blue Cross Blue Shield is currently in the process of developing incentive programs for practice transformation that includes continued funding.
5. The Michigan Care Improvement Registry (MCIR) provides an excellent platform to add onto to assure that the medical home provider has all of the necessary information to assure coordination, comprehensive care without duplication.

Prioritized Recommendations (outcomes from Strategic Planning)

- *1. Develop consensus definition for CYSCHN family-centered medical home and all subsets of medical home such as care coordination in Michigan and method to operationalize that fully involves family representation in each group and process from start to finish.***
- 2. Full integration of all existing programs (American Academy of Family Physicians, Blue Cross Provider Group Incentive Program, Michigan Primary Care Consortium etc.) including those that are community-based.**
- *3. Address the funding and reimbursement issues allowing for multiple strategies.**
- 4. Develop mechanisms to educate the public, consumer and train professionals (Training Programs, Medical community process, CME, Academic detailing Colleges of Nursing etc.).**

***High priority as determined by participants at the Strategic Planning session.**